



Ucare

The Caregiver Guide

Module 10

Community Supports for Remaining at Home

Leader Guide

Module 10

Community Supports for Remaining at Home

PURPOSE

Module 10 is designed to teach caregivers how to support a family member to remain at home despite failing health or to return home after an illness or injury. It will teach you how to obtain help with daily, weekly or monthly tasks. These tasks may include personal care for your family member, household chores, or other necessary tasks for maintaining your family member at home. Information will be included about where to apply for and locate services and/or funding to help pay for support services.

OBJECTIVES

After completing this module, participants will be able to:

1. Identify areas where you need help and create a checklist.
2. Identify sources for getting volunteer help with tasks on your checklist.
3. Describe the types of services that you need that are available from public programs.
4. Identify where and how to get services and/or funding to help pay for in-home and community support services.

SLIDE 1

UCare: The Caregiver Guide Community Supports for Remaining at Home

INTRODUCE

Introduce the trainer(s) and each person in the room. Ask participants about their roles.

NOTE

This is an excellent time to set the tone of the training. Be friendly, relaxed and focused. Remember names.

TELL

The handouts are yours to take home. There is room to write on handouts.

ASK

What would you like to get out of the training today?

NOTE

Put responses on a white board and refer to them during the training. Put a check by specific topics discussed.

SLIDE 2

After completing this module, you will be able to:

- Identify areas where you need help and create a checklist
- Identify sources for getting volunteer help with tasks on your checklist
- Describe the types of services available from public programs
- Identify where and how to get services and/or funding to help pay for in-home and community support services

NOTE

Refer to additional objectives requested by participants.

If participants request topics that are covered in other UCare modules, tell them they can request additional training. Point to the list of UCare modules inside the front cover of the Participant Booklet.

This module will not cover technical questions about eligibility for public programs such as Medicare, Medicaid, Alternatives or Caregiver Support programs. These questions will need to be answered by an eligibility specialist for the particular program.

TELL

In this workshop we will be giving examples of our experiences that may be difficult for some. Remember to respect the confidentiality of group members. What is shared among the group does not leave the room.

This module will help you learn ways to support your family member to return home after an illness or injury, or to remain

at home despite failing health. You may need help with daily, weekly or monthly tasks. These tasks may include personal care for your family member, household chores, or other necessary tasks for maintaining a home. You may need relief at times from your caregiving role. These supports are necessary if you are to maintain a stable home for your family member.

ASK

Is it safe to say, we all want to live in our own home? Why is that? What does “home” mean to you?

NOTE

Write responses on the board. If needed, prompt them with statements such as:

- Home is where we want to be when we are hurting or vulnerable.
- Healing occurs best when we are in a comfortable environment.
- Home feels safe.
- “There’s no place like home.” – Dorothy in Wizard of Oz

TELL

Now let’s discuss your role as caregiver. Because you are attending this class, we assume that you have some role as a caregiver. Some of you may be new to the caregiver role, or perhaps you do not perceive yourself as a “caregiver” at all. Some others in the group may have been in the role for some time with gradually increasing responsibilities. There may be days where you feel overwhelmed. You may feel that it is impossible to get everything done. You may feel that the needs

of your family member are progressing beyond your ability to provide care. You don't know where to turn. So what can you do? Where can you get help?

SLIDE 3

Your role as a caregiver:

- For whom do you provide “care”?
- What do you do for the person?

ASK

Do you perceive yourself as a caregiver? Please share with the person next to you how you are a caregiver. (If the group is small, ask participants to share with the entire group.) For whom do you provide care? What do you do for that person?

TELL

In this module we will help you identify the areas where you need help and recommend how to get it. Each person's needs are unique and complex, so there can be no single program that is likely to provide all that you need. So we will begin with a process of helping you to assess your situation. Then we will provide information about where and how to get help.

SLIDE 4

Assess your situation:

- Check tasks that your family member is unable to perform by him/herself
- Check tasks that the caregiver is unable to perform or finds difficult to perform

TELL

Here are some examples of caregiver situations:

Nancy is a small woman who lives with her 6'5" father with multiple sclerosis. He is no longer able to bathe himself. Nancy is afraid that he will fall in the shower.

Merle is a caregiver for his spouse Carol, who has diabetes. She is no longer able to check her own blood sugar and prepare her insulin due to a visual impairment. And, Merle needs help planning healthy meals for her.

Carla cares for her brother who has AIDS. He is unable to maintain his home and yard and the neighbors are complaining that his lawn is overgrown and unsightly.

ASK

What are the tasks that must be performed daily, weekly and monthly to maintain your family member at home?

ACTIVITY 1

Tell participants to go to page 4 in the Participant Booklet and complete the form "Checklist of Needs" [page 24 of the Leader Guide]. Tell them to put a check by those items that their family member is not able to perform by him/herself. Also check those items such as housekeeping tasks that the caregiver is unable to perform or finds difficult to perform. If there are needs that you and your family member have that are not on the list, add them in the blank spaces. Once you have completed the checklist you are ready for the next step. Give participants about 5 minutes to complete this checklist.

NOTE

Be sure that each participant has a pen or pencil. You may need to provide them.

ASK

How can you find where to get help with the tasks on your checklist?

TELL

To begin, start with your family, friends, and groups of which you are a member, such as a church. You should explore the willingness of those closest to you to assist you and your family member before going to public agencies. Why? Because they may want to help. They want to support you in the goal of helping your family member remain at home. Perhaps you have never asked for help because you didn't want to be a burden on others. You may find that people are very willing to help you in small or large ways that you did not expect. They may not know what you need. So you need to ask.

One way to begin a conversation would be to show your completed "Checklist of Needs." This provides a nice way for them to pick tasks that they like to do and you get the help you need. It becomes a real win-win for everyone involved. You get help. Your helpers get satisfaction from helping.

SLIDE 5

Where to start?

- Family
- Friends
- Neighbors

ASK

Do you get help from your family and friends? Was it difficult to ask? How did you do it?

SLIDE 6

Where else to get help?

- Churches
- Other groups
- Call 211 or go to www.UCare.utah.gov

TELL

If your family and friends are doing all they can, you need to branch out beyond your inner circle and contact community organizations that can help. Which ones you contact will depend on the kinds of help you need. For example, someone from your church may be able to provide respite once a week so that you can go grocery shopping. Perhaps the neighborhood scouts could help with spring or fall yard cleanup. Your neighbor may be willing to launder your sheets and towels when she does her own.

If none of these strategies gets you the help you need, or if there are still things on your list that you can't get help for, you

can look for agencies that have programs for specific kinds of services. Maybe some of the things on your list require special skills. There are pros and cons of using agency services.

ASK

How many of you have gone to an agency to get help? What agencies have you used? What are the advantages?

SLIDE 7

Advantages of agency services:

- Provide you with a needed break
- Relieve you of tasks
- Prevent or postpone institutionalization
- Relieve your family member of feeling like a burden

ASK

What are some reasons people might be reluctant to use agency services?

SLIDE 8

Reluctance to use agency services:

- Caregivers may feel like they are not doing their duty
- Don't want to use government services
- Privacy concerns
- Bureaucratic hassles
- Don't know what services are offered

TELL

If you make the decision to request assistance from an agency, your family member will have to meet the qualifications set by the agency or funding source.

Refer to your checklist. There are different resources available depending on what you need. Agency funding is usually tied to different types of needs. It's helpful to understand five categories of services.

ACTIVITY 2

Ask participants to look at the Glossary on pages 26 and 27. As we continue the training and as you work with agencies, you may find that some terms are not familiar. Tell them to use the Glossary to help them better understand new terms. For instance:

Activities of Daily Living (ADL) are personal care activities necessary for everyday living, such as eating, bathing, grooming, dressing and toileting; a term often used by healthcare professionals to assess the need and/or type of care a person may require.

Instrumental Activities of Daily Living (IADL) are more complex activities, not necessarily done everyday, but which are important to independent living. Examples include preparing meals, doing housework, doing laundry, using transportation, shopping, managing money, using the telephone, and doing home maintenance.

ASK

Listen to the descriptions of the following five categories of service, and decide if and how the tasks on your list fit into these areas.

SLIDE 9

Categories of in-home services:

- Home health
- Personal care
- Homemaker/Chore services
- Respite care
- Hospice

ACTIVITY 3

Ask participants to look at Chart B on page 10 in the Participant Booklet titled: “Guide to In-Home Supports” [page 25 of the Leader Guide]. Follow along with the chart as the Leader describes each of the services, who can provide them and where to obtain funding. As we review Chart B remember to look at the qualifications of who can provide services.

TELL

1. Home health services

Home health services are typically approved by a physician and supervised by a health professional such as a nurse. The services are provided in a person’s home by a licensed health professional who is qualified to perform the tasks needed by the patient. The home health professional may oversee wound care, transfusions, chemotherapy or ostomy care. A Registered Nurse may administer wound care or replace

catheters. Licensed therapists such as a physical or occupational therapist may supervise therapies in the home. A certified nursing assistant (CNA) may provide hands-on assistance such as bathing or dressing, or stand-by assistance such as reminding a patient to take their own medications.

2. Personal care

Personal care services (also called personal attendant, personal assistance services, or PAS), can help with “activities of daily living” (ADL), such as bathing, toileting, getting dressed, or eating. PAS may also provide help with “instrumental activities of daily living” (IADL), such as meal preparation, shopping and housekeeping.

Some PAS services are “participant-directed” which means that the individual has control over the hiring, supervision and retention of the personal attendant. [Refer to Module 11 for more information about hiring a personal attendant.] You may be able to hire a friend, neighbor or another family member to do these things for the person in need. You are not permitted to hire the spouse of the Medicaid recipient with Medicaid funds. You can locate personal attendants through a home health agency.

Another service category called “companion services” can be used to support community activity to prevent isolation of the person. Companion services may assist with such tasks as cooking, shopping and getting to appointments for a person who is unable to do these things for themselves. The housekeeping or other supports must be incidental to providing companionship and not the primary purpose of the visit.

3. Homemaker / Chore services

Homemaker services are “light” household activities such as meal preparation, laundry and routine household care.

Homemaker services are provided to maintain a clean and sanitary living environment for the individual.

Chore services are “heavier” housework such as washing floors or walls, shoveling snow, or making repairs to make the home safe. These services are provided to help seniors and people with disabilities remain in their homes. Providers of these services must have a current business license that permits them to provide the services.

4. Respite care

Respite care services are “relief” for the caregiver. Respite care can be provided in the home to give the caregiver a break from 24/7 responsibility. Respite care may be provided by a companion, a neighbor, or a personal attendant from an agency. As with the home health and personal attendant services, individuals must pass a criminal background check in order to provide these services. Respite may also be provided outside the person’s home, such as a day program for a few hours, or a residential care facility overnight or for several days.

5. Hospice

Hospice services provide special care for individuals who are near the end of their life and for their families either at home, a special facility or a hospital. Hospice provides comfort rather than lifesaving heroic measures. The services address the emotional, social, financial and spiritual needs of individuals who are terminally ill and their families.

ASK

Does your family member need home health services?

SLIDE 10

Where to find out about home health services:

- Contact your health plan first
- Locate a home health agency on the Utah Department of Health website: <http://health.utah.gov/hflcra>. Click on Facility Info, then Listing by County.
- Call the Utah Association for Home Care at 801-466-7210 or go to www.ua4hc.org
- Call 211 or go to www.UCare.utah.gov

TELL

If your family member is being treated for a medical condition, his or her health care provider is the first place to start to ask about home health services. Your family member's doctor or health plan can recommend a home health agency. Your health plan may have a contract with a particular Home Health Agency and you are required to use that agency in order for the plan to pay. Medicare, Medicaid, and other health insurance plans may pay for home health services on a short term basis if your doctor states it is medically necessary.

The Medicaid Aging Waiver, Home and Community Based Alternatives program or The Utah Caregiver Support program may provide home health services on a longer term basis to prevent the person from having to go to a nursing home. Each of these programs has different rules for eligibility.

If you don't have insurance and can pay privately, contact a home health agency directly. They are listed in the yellow

pages, or you can call the state Health Facility Licensing Bureau (800-662-4157) or visit <http://health.utah.gov/hflcra> to get a list of licensed home health agencies in your area. This website also has “report cards” for all health care facilities licensed in the State of Utah. A report card lists complaints that have been investigated against that agency.

ASK

Does your family member need personal care, homemaker or respite services?

SLIDE 11

Where to find out about personal care, homemaker or respite services:

- Contact your local Area Agency on Aging (877-424-4640) or www.utahagingservices.org
- Call 211 statewide or go to www.UCare.utah.gov
- Utah Division of Services for People with Disabilities, Physical Disability Waiver program 800-837-6811 or go to www.hsdspd.utah.gov
- Alzheimer’s Association
- Family Support Centers

TELL

The first place to start to learn more about finding personal care, homemaker or respite services is your local Area Agency on Aging (AAA). These agencies are an excellent source of information about community programs. Whether you are able to pay for the service yourself, or are looking for financial assistance, the AAA has knowledgeable specialists who can provide information. The AAA administers several programs

that provide funding for community supports for low income individuals for adults with disabilities as well as for seniors.

UCare supports an information and referral center that is comprehensive source of information about community services. You may contact UCare by phone or go to the website. The website has a nice search function.

ASK

How do you decide if your family member needs hospice?

SLIDE 12

Where to find out about Hospice:

- End of Life Care Partnership
- www.carefordying.org or call (801) 892-0155.

TELL

Many people who have spent time with a loved one at the end of life and have had hospice services, say that they wish they had gotten hospice earlier. Your family member's health professionals are able to advise you about the benefits of hospice and the timing of when to request it. To find out about hospice services in Utah, contact the End of Life Care Partnership at www.carefordying.org or call (801) 892-0155.

ASK

How do you find out if your family member qualifies for any of these public programs? Which ones should you apply for?

SLIDE 13

For information about eligibility for public programs:

- See the eligibility specialist at the particular agency

TELL

This training is intended to provide general information about the kinds of services that are available to support a person in the community. We will not provide detailed information about eligibility for the different programs. That is the job for the eligibility specialists at the various agencies. This training prepares you to explain your needs and understand the kinds of services that are available to help you and your family member. See the list of agencies in the Resource section of the participant booklet.

ACTIVITY 4

Review Chart C on page 18 of the Participant Booklet titled “Public Funding for Community Supports” [page 26 of the Leader Guide]. This chart lists the services down the left hand column, and the public programs that provide community supports across the top. The dots show which services are covered by the different funding sources.

TELL

Do you have any questions about the funding sources? The leader is not an expert in program eligibility, and we don’t want to give you any misinformation. We will make a few general comments about public programs and long term care services.

SLIDE 14

Medicare:

- Does not pay for long term care
- Pays for medically necessary services by a licensed health professional
- Short term

TELL

Medicare does not pay for long term care. You will notice on Chart C that Medicare only pays for home health services, medical equipment and supplies, and hospice. Medicare will only pay for a licensed health professional to provide home health service when it is determined to be medically necessary on a short term basis. Medicare will provide hospice services if the physician states the individual has less than six months to live. Medicare does not provide long term in-home care or nursing home care.

SLIDE 15

Medicaid is for people with “low income” and “low assets”:

- Must either have a disability or be 65 years of age or older
- Low income
- Low assets

TELL

Medicaid is for people who have low income and low assets. If an individual has assets over the limit, they must use their resources to pay for their medical care until their assets are below the limit. The Medicaid program is different in every state, so be sure you

get information about Utah Medicaid. You may apply for Medicaid at the Utah Department of Health or Department of Workforce Services offices. Or you may apply online at www.utahclicks.org (available in most areas). Call the Medicaid Information Line at 1-800-662-9651 for more information.

SLIDE 16

Medicaid Aging Waiver:

- The Medicaid Aging Waiver allows persons to have greater income and assets than regular Medicaid.

TELL

The Medicaid Aging Waiver is different from regular Medicaid because it allows special income deductions to meet living expenses, exempts income from a spouse even if they are living with the person, and has a separate formula for calculation of assets. Clients receive all of the standard Medicaid benefits as well as the additional benefits of the Aging Waiver. Your local Area Agency on Aging (AAA) takes applications for the Medicaid Aging Waiver.

SLIDE 17

The Home and Community Based Alternatives Program:

- Persons must be at risk for a nursing home placement

TELL

To be eligible to participate in the program a person must: 1) be 18 years or older, 2) be at risk of nursing home placement, 3) have health and personal needs which can be adequately met in the community within established cost limits, and 4)

have low income and minimal assets. Services are based on a care plan developed by a case manager.

Financial eligibility for the Alternatives Program is determined by the AAA case manager. Individuals who qualify for the program may be required to pay a small fee based on a sliding fee schedule. This state-funded program limits how much can be spent for each individual. Your local Area Agency on Aging (AAA) takes applications for the Home and Community Based Alternatives program.

SLIDE 18

Utah Caregiver Support Program:

- The Utah Caregiver Support Program provides information and support to caregivers

TELL

The Utah Caregiver Support Program provides information, assistance, support, caregiver training and counseling to: 1) caregivers of adults 60 years or older; 2) caregivers 60 years of age who are caring for persons with mental retardation and related developmental disabilities; and 3) grandparents or older individuals who are relative caregivers of a child younger than 18.

This program is a good resource for information about in-home supports for individuals who have resources to pay privately, but who need information about where to find providers, help with care planning, counseling, etc.

The program also provides respite and supplemental services to caregivers of adults over 60 who are unable to perform at least 2 activities of daily living. The program is funded through the federal Older Americans Act. For information and application, contact your local AAA.

SLIDE 19

Private pay:

- Contact your local Area Agency on Aging for information
- Private care managers may help you plan and locate services

TELL

Many individuals and families have resources to pay for in-home supports but do not know where to get information. They may need assistance with care planning, counseling, and support to navigate the many private service providers, agencies and programs. Again, the AAA is a good place to start. The Utah Caregiver Support Program provides information and counseling to individuals regardless of their ability to pay. Private care managers can also help plan, locate and arrange services for a fee.

TELL

Ask participants to go to page 20-27 in their Participant Booklet. The following pages list resources available to you. Review some of the resources with the group, as appropriate.

ASK

You have learned about many resources today. What is one new thing you have learned from this training? Do you have any questions or comments?

NOTE

List responses on the board. Review objectives. Ensure all have been covered.

SLIDE 20

- You don't have to do it all.
- It's okay to ask for help.
- Community support programs are available

REVIEW

In this class you have learned about community supports that are available to support your family member to remain at home despite failing health or to return home after an illness or injury. You learned to use a checklist to identify tasks with which you need help. You learned some strategies for getting help with tasks on your checklist from friends or neighbors. And finally you learned about some public programs where you may be able to get services and funding to help pay for in-home and community support services.

SLIDE 21

Take a Break.

NOTE

Leader should choose one of the “Take a Break” exercises from the Leader’s Toolkit.

TELL

We have one remaining activity. An important part of caregiving that is often forgotten is YOU, the caregiver. You need to take care of yourself.

ACTIVITY 5

Lead participants in the “Take a Break” exercise you have chosen. Impress on participants that it is important for them to do something for themselves each day. Ensure they understand the “Take a Break” card. Review with them and ask questions to ensure understanding.

SUMMARY

Remember that you have courage, strength, compassion, power and wisdom. Thank you for your participation. You’ve been a great audience. Please complete the Feedback sheet. I welcome your comments and appreciate your interest. I wish you the best in your efforts to care for your family member. If you have additional questions or concerns, I would be happy to talk with you following this presentation.

Chart A: Checklist of Needs

Home Health			Personal Care			✓
Medication reminder		Wound care		Bathing		Dressing
Tube feeding		Chemotherapy		Grooming		Toileting
Catheter		Dialysis		Eating		Transferring
Check blood sugar		Transfusions		Making self understood		Ability to understand
Insulin injections		Ostomy care		Answer phone		Make phone calls
Medical transportation		Tracheostomy		Meal prep		Housekeeping
Medical equipment		Medical supplies		Shopping/ errands		Transportation
Physical therapy		Occupational therapy		Exercise / Getting out		
Homemaking			Chore Service			
Vacuum		Change linens		Wash walls		Shampoo carpets
Banking		Laundry		Clean windows		Move furniture
Pay bills				Yard work		
Respite						
In home companion		Adult Day Care				
Overnight out-of-home						

Chart B: Guide to In-Home Supports

What tasks do they help with?		Who can provide?
Home Health Services	Nursing services such as dressing wounds, changing catheters, or therapy services	Licensed health professionals ²
	Hands-on or stand-by assistance with activities of daily living , such as, bathing, dressing, reminders to take medications	Certified Nursing Assistant (CNA) ²
Personal Care Services	Personal attendant services are <i>participant-directed</i> help with personal care such as bathing, dressing, cooking, eating.	Friend, family member ¹ , home health worker ²
	Companion services support community activity and prevent social isolation, and can help with cooking, laundry, shopping.	
Home-maker / Chore Services	Homemaker services are “light” household tasks such as, cooking, cleaning, laundry.	Friend, family member ¹ , trained homemaker ³
	Chore services are “heavier” household tasks such as washing floors or walls, yard care, snow removal.	Neighbor, chore service agency ³
Respite Care Services	In home relief for caregiver	Family member ¹ , friend ²
	Out of home stay	Licensed facility
Hospice	Nursing services, personal care , social services, physician visits, counseling, and homemaker services, pastoral care	Hospice team (physicians, nurses, social workers, clergy, volunteers)
		Licensed hospice facility or hospital

¹ Spouse cannot be paid to provide services under Medicaid

² Need a criminal background check and current first aid certification

³ Must have current business license to provide the service

Chart C: Public Funding for Community Supports

	Medicare	Medicaid	Medicaid Aging Waiver	Alternatives Program	Utah Caregiver Support Program
Home Health – Licensed Health Professional	•	•			
Home Health – CNA	•	•	•	•	•
Personal Attendant Service		•	•	•	•
Companion Service			•	•	•
Homemaker Service			•	•	•
Chore Service			•	•	•
Respite Care Service			•	•	•
Fiscal Management Service			•	•	
Transportation		•	•	•	
Medical equipment and supplies	•	•	•	•	•
Case Management		•	•	•	•
Adult Day Care		•	•		•
Individual Counseling		•			•
Support Group		•			•
Home Delivered Meals			•	•	
Hospice	•	•			